

FAC MINUTES

January 20th, 2018 9:30 AM to 4:00 PM Topeka

In Attendance

Donna, Deanna, Kacy, Cassandra, Margie, Debbie, Sookyung, Terrance, Heather, Kayzy and Leah.

Guests: Lorelee, Allison, Jen and Liz

EHDI (Early Hearing Detection and Intervention)

- NBHS is funded through a Hersa grant and will have to reapply after three years.
- Will be creating a deaf mentor program.
- Working on a family liaison to help guide kiddos/family
- The family support network was created about a year and a half ago.
- SoundBeginnings is collaborating with sound start. Sound start provides early intervention for kids with hearing loss.
- Key Players: Parents, Support Parents and Coordinator.
- The support parent must contact the new parent within 48 hours by phone after a parent has requested support. Contact will be made three times in four weeks.
- After four weeks a survey will be sent out to supporting parent and the matched parent. This is to ensure both parents are happy with their matches.
- The coordinator recruits, trains and assists supporting parents. Coordinators are also responsible for making "matches" and spreading the word of "Parent to Parent". Lorelee is the Coordinator for Parent to Parent and will be managing the family support network database.
- Parent matches are based upon what they want to be connected on.
- About 70 kids a year are diagnosed with hearing loss through the newborn hearing screen.
- Once the request form is filled out an email will be sent to Lorelee. From there she will send out an email to the parent to notify them of a match. She will also be creating Flyers and Brochures.
- Family Liason will work with the families for the first 6 months and hoping to extend that out to the first full year. This person will also provide care coordination to the family.
- Language assessment is a standard education test to see if the child is still developing spoken language and is ready for school. This is only for children who are deaf or hard of hearing.

Supporting You

- Measurables: number of successful matches and how many. Number of total matches vs the number of successful matches. Successful matches would be number of mentors and mentees that complete a positive survey regarding their match.
- After a certain amount of time, mentors need to be retrained.
- Terms to use Refereed parent and supporting parent. Not mentor and mentee.

- Require limited basic information from person receiving services form Supporting You.
- “ If you’re interested in supporting you, go to this website to register” have the formal registration as a mailer and include link to the website for full registration.
- Should we background check people? If so who? Should this be included in training? This is to ensure you’re not giving sensitive information to a predator or someone who would want to harm you or your child.
- Create profiles for parents, that way you can see your matches profile. You would also be able to communicate and or get contact info. Can also use profile to opt out of program if you would like.
- Need to create a Supporting parent survey as well as a Refereed parent survey. Make sure there is an option to be anonymous. Email or texting options.
- We need to create a way to a log of unhappy surveys to provide follow up. How would we flag these?
- Individual projects:
 - Heather, Kazy and Leah will meet with “POPS”.
 - Kacy will join in on the conference call with Johnny about the data system.
 - Donna will create flow chart of Parent calls.
 - Sookyung will create survey questions.

Updates

- Birth Defects Launched this month and is working on a pilot project.
- Newborn Screening has been working towards screening for critical metabolic conditions. All of the birthing facilities are doing the Newborn Screen. Only 84% of the screenings are being done within those facilities.
- Newborn Screening advisory council is voting to add additional metabolic diseases such as critical congenital heart defects.
- Children’s Mercy hasn’t seen any babies that had a congenital heart disease that wasn’t picked up by the Newborn screening.
- Infant Toddler Services will we conducting a state wide needs assessment starting this spring.

Announcements

- New Sheets for the New Member Orientation Packet will be printed and brought to the March meeting.
- Heather will be emailing out House Bills and Senate Bills that pertain to the FAC. They will come frequently and won’t be batched.
- Look at your calendars to see if we need to change the March and May meetings of 2019.
- FAC logos!
- If you’re interested in reviewing aid-to-local apps, contact Kayzy. Training will be provided at the March meeting.



Next Meeting

March 24th, 2018 in Salina, KS